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Comparative Approaches to Genetic Discrimination: Chasing Shadows?

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Genetic discrimination (GD) is one of the most pervasive issues associated with genetic research and its large-scale implementation. An increasing number of countries have adopted public policies to address this issue. Our research presents a worldwide comparative review and typology of these approaches. We conclude with suggestions for public policy development.

Genetic Discrimination

Research in genetics and related fields has already enabled the development of diagnostic and predictive tests as well as pharmacogenetic drugs [1]. Genetic information is also increasingly used outside the medical context for ancestry, paternity, and forensic investigations (Box 1). Within the past 30 years or so, GD – the adverse treatment or profiling of individuals, or their relatives, on the basis of their actual or presumed genetic characteristics – has become one of the most pervasive and mediatized issues associated with genetic research and its implementation in developed countries [2].

Similarly to racial, sexual, and ethnic discrimination, GD can lead to exclusion and loss of social opportunities; it is also strongly associated with psychological distress [3]. Anxiety about GD has been identified as an important reason why

individuals decline to participate in genetic research or to undertake medically recommended genetic tests [4]. The potential for genetic information to be abused by society has been taken very seriously by the public and experts alike, giving rise to the concept of ‘genetic exceptionalism’ in the mid-1990s [5]. According to this viewpoint, genetic information is more sensitive than other types of medical information and should be protected more stringently.

Growing political activism has influenced policymakers in a large number of developed economies to adopt laws, policies, moratoria, and guidelines to prevent GD. Here we present a comparative overview of existing approaches worldwide (Figure 1).

Comparative Law and Policy Review (Figure 1)

International Overview

In 1997, UNESCO’s Declaration on the Human Genome and Human Rights stipulated that ‘No one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity.’ There is now a consensus among international organizations that the confidentiality of identifiable genetic information should be protected and that discrimination should be prevented. (Table S1 in the supplemental information online).

Regional and National Overview (Figure 1 and Table S1)

Europe. Two legally binding regional instruments, the Charter of Fundamental Rights of the European Union (2012) and the Convention on Human Rights and Biomedicine (1997), have influenced members of the European community to develop national instruments to address GD based on the human rights approach. Furthermore, a recent recommendation of the Council of Europe (2016) proposes that insurers justify the processing of all health-related personal data and not require genetic tests, or use test results, for insurance purposes (<http://www.quotidianosanita.it/allegati/allegato2027308.pdf>).

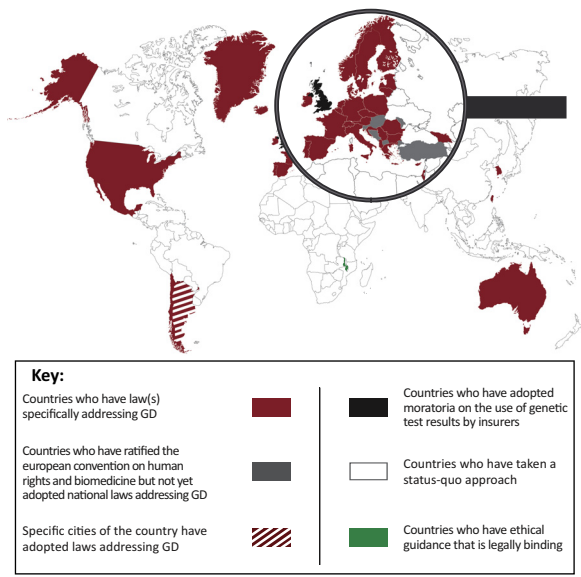
The British government, preferring a different approach, has opted to prevent GD through a moratorium. This flexible and provisional solution was agreed upon by the government and the Association of British Insurers (ABI) in 2001 (in force until 2019). The moratorium prevents members of the ABI from using the results of predictive tests unless pre-approved by the government following consultation with independent experts. As moratoria are flexible, they can be easily updated to account for new scientific developments. Another outlier that was not influenced by genetic exceptionalism is The Netherlands’ Law on Medical Examinations (1977) (unofficial translation). In this law access to medical information by insurers depends on the level of coverage

Box 1. Overview of GD Outside the Contexts of Insurance and Employment

European immigration laws are fairly liberal in authorizing the use of genetic information by governmental agencies. For example, many countries allow the use of genetic tests to confirm biological filiation in the context of family reunification for immigration [10,11]. The Prüm Convention (2005) allows signatories to share these test results with each other. In the USA, governmental agencies have reported increasing interest in using genetic information in criminal investigations. The US National DNA Index (NDIS) currently contains over 12 647 876 offender profiles, 2 551 917 arrestee profiles, and 744 611 forensic profiles, making it the largest DNA database in existence^v. In some states permissive forensic investigation techniques using genetic data for matching purposes have been authorized [12]. In Hong Kong, a disturbing public awareness campaign concept regarding street littering used genetic information from volunteers to create facial composites. These reconstructed faces were featured in posters that were displayed in high-traffic areas to raise awareness about littering^v. In Kuwait, Law no. 78/2015 created controversy by making it mandatory for citizens, visitors, and permanent residents to provide DNA for storage in the country’s database for law enforcement and possibly paternity cases. The government has now delayed its implementation and set up the law for review^{vi}.

Worldwide normative approaches to address genetic discrimination

Countries are considered as "having an approach" whether the said approach addresses genetic discrimination specifically in part, or broadly.



APPROACH	SUMMARY	EXAMPLE	HIGHLIGHTS
Human Rights	This approach aims to provide a broad, human rights based protection against GD by including it as an illicit ground of discrimination in a country's human rights legislation.	Albania, <i>Law No. 10.222 dated 4.2.2010 on protection from discrimination</i> (2010)	Broadly formulated, prohibition vulnerable to judicial interpretation and statutory exceptions. Offers a degree of flexibility of interpretation.
Genetic exceptionalism	This approach consists of creating a specific law differentiating genetic information from other types of health or personal information to provide specific, more stringent, protection.	Estonia, <i>Human genes research act</i> (2001, last amendment 2010)	Approach assumes that genetic information is more sensitive than other types of medical information. Purports a rather pessimistic and deterministic view of genetics.
Sectoral prohibition	This approach aims to prevent the processing of genetic information by specific stakeholders through the use of prohibitive clauses in sectoral legislation such as employment, immigration, or insurance laws.	United States, <i>Genetic information non-discrimination Act of 2008</i> (2008)	Application limited to specific types of stakeholders or limited instances of GD. Often formulated too narrowly to protect against GD based on new types of OMICS data and on family history of diseases.
Ethical guidance	Guidelines may be fairly broad in nature and are not legally binding. They may have a different normative strength depending on the specific context.	Singapore, <i>Ethics guidelines for human biomedical research</i> (2015)	Difficult to enforce. Useful to stimulate debate as well as to promote the development of more stringent laws and policies.
Self-regulatory	Under this approach, professional organizations have proposed guidance (ex. policies and codes) to address the challenges raised by GD in their field.	Canadian life and health insurance association Inc., <i>Industry code-Genetic testing information for insurance underwriting</i> (2017)	Relies on the goodwill of specific actors and on nonbinding guidelines to address GD. Model is flexible and can serve as a source of professional obligations. It can also be easily modified to account for new types of predictive data or emerging contexts of GD.
Moratoria	This approach consists of an agreement between a representative professional association and the government, that its members will not make use of genetic information.	United kingdom, <i>concordat and moratorium on genetics and insurance</i> (last renewed 2014)	Temporary approach that could be abandoned to adopt a different model depending on future scientific developments and incidence of GD. Flexible approach, can be easily modified to account for new types of predictive data or emerging contexts of GD.
Status-quo	Stakeholders have not taken any specific action to address GD. There may still be national debates and studies undertaken within the country to determine potential future options.	No special normative protection implemented (ex. Saudi Arabia, Russia, Vietnam, Congo, etc.)	Does not differentiate genetic information from other types of medical data or offer specific protection against GD. Some default protection may be available through existing human rights laws including privacy laws
Hybrid	Some countries have integrated elements from one or more of the other identified approaches to develop their own, multi-layered, personalized format.	Germany, <i>Human genetic examination act (Untersuchungenbei menschen)</i> (2009)	Custom fit governance model that includes aspects of different approaches to provide a more robust degree of protection.

Trends in Genetics

Figure 1. Worldwide Normative Approaches to Address Genetic Discrimination (GD).

being sought. This approach provides for universal access to a minimum 'no questions asked' level of insurance.

North America. Given Canada's universal health-care system and the limited number of documented Canadian cases of GD, policymaking initiatives have been limited. However, the political momentum in Canada has recently swung in favor of the adoption of a legislative solution. Bill S-201, the Genetic Non-Discrimination Act, was adopted by the House of Commons and is now awaiting Royal Assent. It could be subject to constitutional challenges in the coming months. It proposes both a human rights approach, based on genetic characteristics, and a sectorial prohibitive approach to GD. Rather belatedly, Canadian insurers reacted to the growing pressure to regulate GD by promulgating their own industry code, which was updated in January 2017 to include a stipulation that insurers' would not 'use genetic test results for life insurance coverage of \$250,000 or less'¹.

In the USA, the issue of GD is particularly contentious due to the absence of a universal health-care system meaning that access to personal insurance is usually tied to employment. Moreover, claims of GD appeared for a limited number of monogenic diseases early in the advent of the Human Genome Project [2]. In response there is now a patchwork of state laws on GD in various contexts and for various diseases. Following lobbying by patient groups and genetic researchers, the Federal Congress imposed a common minimal threshold across the country through the Americans with Disabilities Act, the Health Insurance Portability and Accountability Act, the Genetic Information Nondiscrimination Act, and the Affordable Care Act. However, the complex US federal framework does not extend to the field of life insurance, for which the only protection available is at the state level, if anyⁱⁱ.

Recently, the Mexican government rallied to the human rights approach by

amending both its Federal Law to Prevent and Eliminate Discrimination (2014) and its General Healthcare Law (2015) to include a general prohibition on discrimination based on the genetic characteristics of an individual.

South America. Most South American countries have yet to address the question of GD in their laws or policies. Given the more modest standards of living, the limited capacity to perform genetic tests, and the costs of insurance, GD is not a priority in this region. Only Chile has provided national protection to its citizens via legislation from GD based on the genetic exceptionalism approach. Argentina has adopted city-specific legislation, such as the 2001 Law of Genetic Patrimony of Buenos Aires (author's translation), which presents a hybrid approach integrating human rights and sectoral prohibitions.

Australasia. Australian researchers have conducted a large-scale investigation of GD in their country [6,7]. The Australian

legislator opted for an interesting approach considering discrimination on the basis of a 'genetic predisposition to a disability' to be similar to 'discriminating based on a disability' and prohibiting such discrimination through its Disability Discrimination Act (1992). However, the Act provides exceptions that substantially limit this protection, including for life insurance. New Zealand chose the *status quo* approach and has not yet legislated on GD. New Zealand insurers (ISI) have adopted a Guide on Genetic Testing limiting its useⁱⁱⁱ.

Asia. Some Asian countries (e.g., Japan, China, South Korea) participate actively in genomic research and personalized medicine. However, South Korea is the only Asian country to specifically prevent GD under a genetic exceptionalism approach in its Korean Bioethics and Biosafety Act. Taiwan's Personal Information Protection Act (2012) includes a general provision on GD but it has multiple exceptions that significantly reduce the level of protection it provides. A few other Asian countries (India, Japan, Singapore, and the Philippines) have recognized the challenge posed by GD in their ethics guidelines but not yet legislated on this matter.

Africa and the Middle East. There has been little normative activity in these regions. Israel is an outlier, having taken a prohibitive approach in its Genetic Information Law of 2000. This law includes broad prohibitions on the use of genetic information in the context of employment and insurance.

The only African country having adopted enforceable measures to prevent GD is Malawi. The National Health Sciences Research Committee (NHSRC) of Malawi has adopted policy requirements based on the Science and Technology Act No.16 of 2003 that are legally enforceable [8]. A few other countries, such as South Africa, have started a timid reflection on GD observable in non-binding guidance on the subject.

Concluding Remarks

The capacity of the approaches we have described to effectively address incidents of GD has been considered in only a few studies [2,7,9]. Existing models generally suffer from several important limitations: (i) lack of public visibility; (ii) restrictive, rigid formulation; (iii) narrow protection; and (iv) complex administrative procedures.

In addition to these challenges it is likely that a large number of GD cases will not be prevented by these approaches since they were developed to address GD in the context of highly heritable monogenetic diseases. Other types of GD and other sources of predictive information are inconsistently addressed by existing norms. Moreover, the laws of most countries liberally sanction the use of genetic information by government to control immigration and prevent crime. The sheer amount of genetic data contained in governmental databases in developed economies warrants the development of more stringent oversight and accountability frameworks.

An implicit question raised by these observations is whether law is truly the best vehicle to address GD. By increasingly deciding to single out, regulate, and protect genetic information, are we not also fostering genetic exceptionalism and the stigmatization of certain types of genetic profiles considered 'at risk'? While legislation may help prevent GD, there could be an even greater need to actively engage stakeholders on the potential and limits of genetic technologies, existing protections, and the need to express greater solidarity in integrating genetics in everyday life. We substantially share our genome with our relatives, our neighbors, and the entire human species, which provides an impetus for giving greater weight to the ethical principle of solidarity in addressing GD.

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Supplemental Information

Supplemental information associated with this article can be found, in the online version, at <http://dx.doi.org/10.1016/j.tig.2017.02.002>.

Resources

ⁱCanadian Life and Health Insurance Association, *Industry Code on Genetics Testing Information for Insurance Underwriting*, www.clhia.ca/domino/html/clhia/clhia_lp4w_Ind_webstation.nsf/page/E79687482615DFA485257D5D00682400

[OpenDocument](#)

ⁱⁱNational Conference of State Legislature, *Genetics and Life, Disability and Long-Term Care Insurance, Genetic Information: Legal Issues relating to Discrimination and Privacy*, www.ncsl.org/research/health/genetic-nondiscrimination-laws-in-life-disability.aspx

ⁱⁱⁱInvestment Savings & Insurance Association of New Zealand Incorporated, *ISI Underwriting Guide*, fsc.org.nz/site/fsc/files/kiwisaver%20Info%20Pdfs/underwriting%20guide%207.pdf

^{iv}Criminal Justice Information Service, *National DNA Index Statistics*, www.fbi.gov/services/laboratory/biometric-analysis/codis/ndis-statistics

^vSouth China Morning Post, *Hong Kong Litterbugs Shamed in Billboard Portraits Made Using DNA from Trash*, www.scmp.com/lifestyle/article/1804420/hong-kong-litterbugs-shamed-billboard-portraits-made-using-dna-trash

^{vi}New Scientist, *Kuwait to Change Law Forcing All Citizens to Provide DNA Samples*, www.newscientist.com/article/2109959-kuwait-to-change-law-forcing-all-citizens-to-provide-dna-samples/

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